



Representative Louise M. Slaughter
Chairwoman, House Committee on Rules
Representing New York's 28th District

PRESS RELEASE

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**Rep. Slaughter, Author of Genetic Information Nondiscrimination Act, Applauds
Bill's Passage in House of Representatives**

Bill To Be Sent to President for Signature

Washington, DC – Congresswoman Louise M. Slaughter (D-NY-28), Chairwoman of the House Committee on Rules, today applauded the passage of the Genetic Information Nondiscrimination Act by the House. Rep. Slaughter, a microbiologist with a Masters in Public Health, authored and first introduced genetic antidiscrimination legislation, thirteen years ago.

The Genetic Information Nondiscrimination Act (GINA) would prevent health insurers from canceling, denying, refusing to renew, or changing the terms or premiums of coverage based solely on a genetic predisposition toward a specific disease. The legislation also bars employers from using individual's genetic information when making hiring, firing, promotion, and other employment-related decisions.

“Since no one is born with perfect genes, we are all potential victims of genetic discrimination,” said Rep. Slaughter. **“This legislation marks the beginning of a new era in health care where a person's genetic information can no longer be used against them.”**

“By prohibiting the improper use of genetic information, Americans will be encouraged to take advantage of the tremendous life altering potential of genetic research,” Slaughter concluded.

Last week, the Senate unanimously approved the bill with minor changes. Today, the House is accepted those changes, clearing the bill for the President's signature.

BACKGROUND

Rep. Slaughter introduced the first genetic antidiscrimination bill in 1995. However, it took the new Democratic Congress to make protection of genetic information a national priority.

During the 110th Congress, Rep. Slaughter, along with Rep. Biggert (R-IL-13), Rep. Eshoo (D-CA-14), and Rep. Walden (R-OR-2), introduced H.R. 493, the Genetic Information Nondiscrimination Act on January 16, 2007. In April 2007, the House passed H.R. 493 by an overwhelming vote of 420 -3. The House reaffirmed its support on March 5, 2008 when it passed the Paul Wellstone Mental Health Parity Act, which included GINA within the legislation.

The Senate had passed this bill unanimously twice in previous Congresses. However, during the 110th there was a hold placed on the bill in the Senate. The yearlong hold was released after lengthy negotiations ended successfully last week.

The measure must now be approved by the House once again before being sent to the President for signature. Given the House's previous support for Rep. Slaughter's legislation, passage is expected.

Support in the White House: On April 25, 2007, the Bush Administration issued a Statement of Administration Policy (SAP) in support of H.R. 493.

Historical Precedents Indicate Need for Legislation: In the 1970s, many African-Americans were denied jobs, educational opportunities, and insurance based on their carrier status for sickle cell anemia, despite the fact that a carrier lacked the two copies of a mutation necessary to get sick.

In 1998, Lawrence Livermore Laboratories in Berkeley was found to have been performing tests for syphilis, pregnancy, and sickle cell on employees without their knowledge or consent for years.

In 2000, the Burlington Northern Santa Fe Railroad performed genetic tests on employees without their knowledge or consent.

Broad Public Support: In 2002, 85 percent of those surveyed by the Genetics and Public Policy Center at Johns Hopkins University did not want employers to have access to their genetic information. By 2004, that number had risen to 92 percent. In 2002, 68 percent of those surveyed said their genetic information should be kept private from health insurers. By 2004, it had increased to 80 percent.

Broad Support Among Health Care Professionals: In one survey of genetic counselors, 108 out of 159 indicated that they would not submit charges for a genetic test to their insurance companies primarily because of the fear of discrimination. Twenty-five percent responded that they would use an alias to obtain a genetic test so as to reduce the risk of discrimination and maximize confidentiality. 60 percent indicated they would not share the information with a colleague, because of the need for privacy and fear of job discrimination.

Over 200 health, medical, and scientific organizations have endorsed GINA.

The full text of Congresswoman Slaughter's prepared remarks on the Genetic Nondiscrimination Act are below:

M. Speaker, the story of humanity is defined by extraordinary achievements that centuries later are looked upon as impacting the course of human history.

Five years ago, we saw one of these distinguishing achievements – a discovery that pries open the door of possibility and presents an opportunity to advance the human race.

The sequencing of the human genome is that achievement.

This breakthrough in the field of genetics joins the ranks of momentous discoveries that have changed the face of medicine and science for centuries to come, like the discovery of the polio vaccine so many years ago.

Last week, Senator Kennedy said it best when he noted that the mapping of the human genome “may well affect the 21st century as profoundly as how the invention of the computer or the splitting of the atom affected the 20th century.”

However, M. Speaker, such discoveries and achievements do not automatically lead to

these extraordinary breakthroughs.

In order for us to fully reap the benefits, we must ensure that our social policy keeps pace with the advancement of our science.

M. Speaker, that is precisely why I rise today in support of the Genetic Information Nondiscrimination Act.

It's been well over a decade in the making, but I am pleased that the House of Representatives is once again considering this bill today – hopefully for the last time, so we can send it to the President to sign into law.

It's been 13 years since I introduced the original version of the bill that is before us today.

And while I am pleased that we are taking it up, I am saddened that so much time has been lost, and that the march toward progress and discovery has been slowed.

The Genetic Information Nondiscrimination Act, or GINA, is the culmination of a broad and bipartisan effort to prohibit the improper use of genetic information in workforce and health insurance decisions.

GINA prohibits group health plans and health insurers from denying coverage to healthy individuals or charging higher premiums based solely on a genetic predisposition to develop a disease in the future.

Furthermore, it bars employers from using one's genetic information when making hiring, firing, job placement or promotion decisions.

M. Speaker, this bill has been described as the first civil rights legislation of the 21st Century.

I think that assessment is correct because, with the exception of trauma, everything that happens to a person's body has a genetic component.

From the color of our eyes, to our height, to the illnesses and disorders we are susceptible to, everything happens because of our genes.

No one – not a single living human being - has perfect genes.

In fact, each one of us is estimated to be genetically predisposed to between 5 and 50 serious disorders.

The good news is that since the sequencing of the human genome was completed in April of 2003, researchers have identified genetic markers for a variety of chronic health conditions, and increased the potential for early treatment and the prevention of numerous genetic-based diseases.

There are already genetic tests for over 1000 diseases, and hundreds more are under development.

To give you an idea of the potential that exists, consider that genetic tests can tell a woman with a family history of breast cancer if she has the genetic mutation that causes it long before the cancer develops.

Armed with this information, this woman can make important health decisions on when to engage in preventative care and when to seek early treatment.

And in doing so, we can cut down on hospital stays and invasive surgeries while allowing medical treatments to be more personalized.

M. Speaker, in addition to improving health care for millions of individuals, genetic testing gives our scientists and medical researchers invaluable insight into how to combat and, perhaps, even cure these diseases in the future.

However, for the potential of genetic research to be realized, we need to make genetic testing something that is commonplace, rather than something that is feared.

Unfortunately, because no one has perfect genes, no one is immune to genetic discrimination.

And the threat of discrimination is holding men and women back from participating in clinical trials that will lead to the medical breakthroughs of the 21st Century.

M. Speaker, their fears are not unfounded. Genetic discrimination is real and is happening today.

A 2001 survey of employer medical testing practices found that 1.3% of companies test employees for sickle cell anemia, 0.4% test for Huntington's Disease, and 20.1% ask about family medical history.

During the 1970s, many African Americans were denied jobs and health insurance based on their carrier status for sickle cell anemia.

More recently, many have heard about the 2002 Burlington Northern Santa Fe Corporation case where the company a \$2.2 million settlement after it tested its employees for a genetic marker dubiously associated with carpal tunnel syndrome.

In North Carolina, a woman was fired after a genetic test revealed her risk for a lung disorder even though she had already begun the treatments that would keep her healthy.

There was even an instance of an adoption agency refusing to allow a woman at risk for Huntington's disease to adopt a child.

These abuses have only fed the public fear of genetic discrimination, leading many Americans to forgo genetic testing even if it may help avert premature death.

66% of Americans are concerned about how their genetic information would be stored and who would have access to it.

72% of the American public believes that the government should establish laws and regulations to protect the privacy of one's genetic information.

M. Speaker, genetic discrimination is wrong on two fronts.

First, it is critical to remember that simply carrying a given genetic mutation does not guarantee that one will develop the disorder.

It merely confers a level of risk upon the carrier.

Given that scientists cannot accurately predict when or whether a carrier will develop a genetic disorder, it is illogical to allow this information to be used by health insurers and employers for discriminatory purposes.

Secondly, and very importantly, if individuals do not participate in clinical trials, we will never be able to reap the real benefits of genetic science.

In a 2003 editorial, Dr. Francis Collins, head of the National Human Genome Research Institute, and James Watson made a persuasive argument in favor of non-discrimination legislation like GINA.

They wrote, and I quote: "Genetic discrimination has the potential to affect people's lives in terms of jobs and insurance, but there is another dimension as well: It can slow the pace of the scientific discovery that will yield crucial medical advances." End quote.

M. Speaker, as I have mentioned, this legislation began 13 years ago and has had quite a ride going back and forth between the House and the Senate.

I would like to take a moment to speak briefly about the evolution of this bill and the agreements that we have made so that it could end up here today.

In order for us to move forward, we addressed some of the concerns about the legislation, specifically about the threat of frivolous lawsuits.

Several years back, we made sure that if an employer inadvertently receives a person's genetic information, they could not be sued unless they used that information to discriminate against the employee.

Within the past few weeks, we were able to work out a clarification regarding the so-called "firewall" issue.

This agreement makes both sides happy and still preserves 40 years of civil rights law by ensuring that employers are held accountable under civil rights remedies.

In addition, this bill requires that before an individual can go to court, the EEOC has to review their claim and determine if it has merit.

I am very pleased that we were able to work together to ensure the success of this critical legislation.

And, M. Speaker, while there have been some opponents to this bill over the years, there have mostly been allies.

I hold here in my hand 514 letters of support from a wide spectrum of health, scientific, and medical-related organizations.

Here in Congress, we have over 220 cosponsors, both Democrats and Republicans.

Just over a year ago, this body passed GINA 420-3, and last week, the Senate once again passed this bill unanimously by a vote of 95-0.

Even the White House has come out in support of genetic nondiscrimination legislation.

Before I close, I want to take a moment to thank the lead Republican cosponsor of this bill, Congresswoman Judy Biggert. Without her and her staff's hard work, today would simply not have been possible.

I also want to thank Congresswoman Anna Eshoo for her strong advocacy on behalf of this bill over the years.

I want to thank Senators Kennedy, Snowe and Enzi for championing this bill through the Senate.

And I especially want to thank Dr. Francis Collins for his support. His testimony last year before three House Committees should have swayed even the firmest non-believers that genetics has the potential to change our health care system as we know it.

I am so proud to have played a role in making this legislation possible – legislation that not only will stamp out a form of discrimination, but will allow us to realize the tremendous potential of genetic research.

By passing this legislation today, we open the door to usher in a whole new era of health care and change the course of human history.

Millions of Americans have waited far too long for these protections, but I'm so pleased the wait is almost over.

I urge all my colleagues to support this bill once again.

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